

# How is quality of life defined by palliative care patients?

## A systematic review & synthesis of qualitative research

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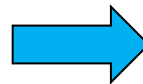
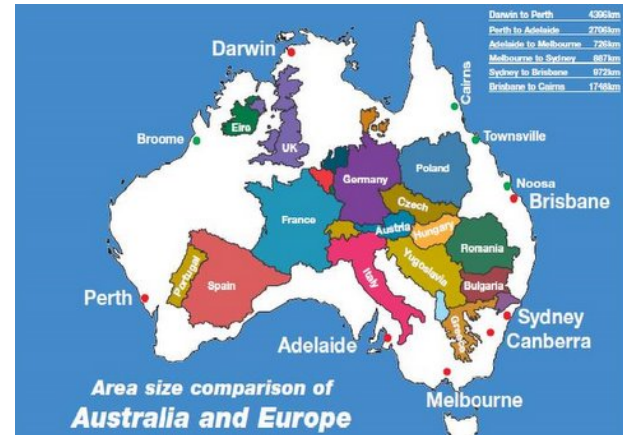


# Overview

- Economic evaluation in palliative care
- Systematic review
- Framework synthesis
- Key themes
- Implications for measuring benefits in palliative care economic evaluations



# Economic evaluation



# Measuring benefits

- Quantity AND quality
- Health-related quality of life
  - **EQ-5D**: Anxiety; pain; mobility; self-care; usual activities
  - **SF-6D**: Mental health; pain; physical function; role limitation; social function; vitality

**McCaffrey N** et al *PLoS ONE* 2014;9(4):e94316.

**McCaffrey N**, Currow DC & Eckermann S. *JPSM* 2009;37(6):e7-e9.

# Aims

- To determine the QOL domains important to adults receiving palliation from their own perspective for validating preference-based instruments used in economic evaluations.
- To compare and contrast important aspects of QOL according to country of origin, primary diagnosis, living arrangements and proximity to death.

# Methods

## Search terms

Palliative

Terminally ill

Qualitative

Quality of life

Quality of dying

## Databases

1. ASSIA
2. CINAHL
3. Cochrane Library
4. Embase
5. Medline
6. Psycinfo
7. Pubmed

# Inclusion criteria

Study Design	Study Population
Qualitative methodologies	People $\geq 18$ years of age
Report original data	Life-limiting illness
Analysis with quotations	Receiving palliation
Study Aim	Study Publication
Quality of life is the focus	English language
No pre-conceived list	Peer-reviewed journal



# Study selection

- **Titles and abstracts**

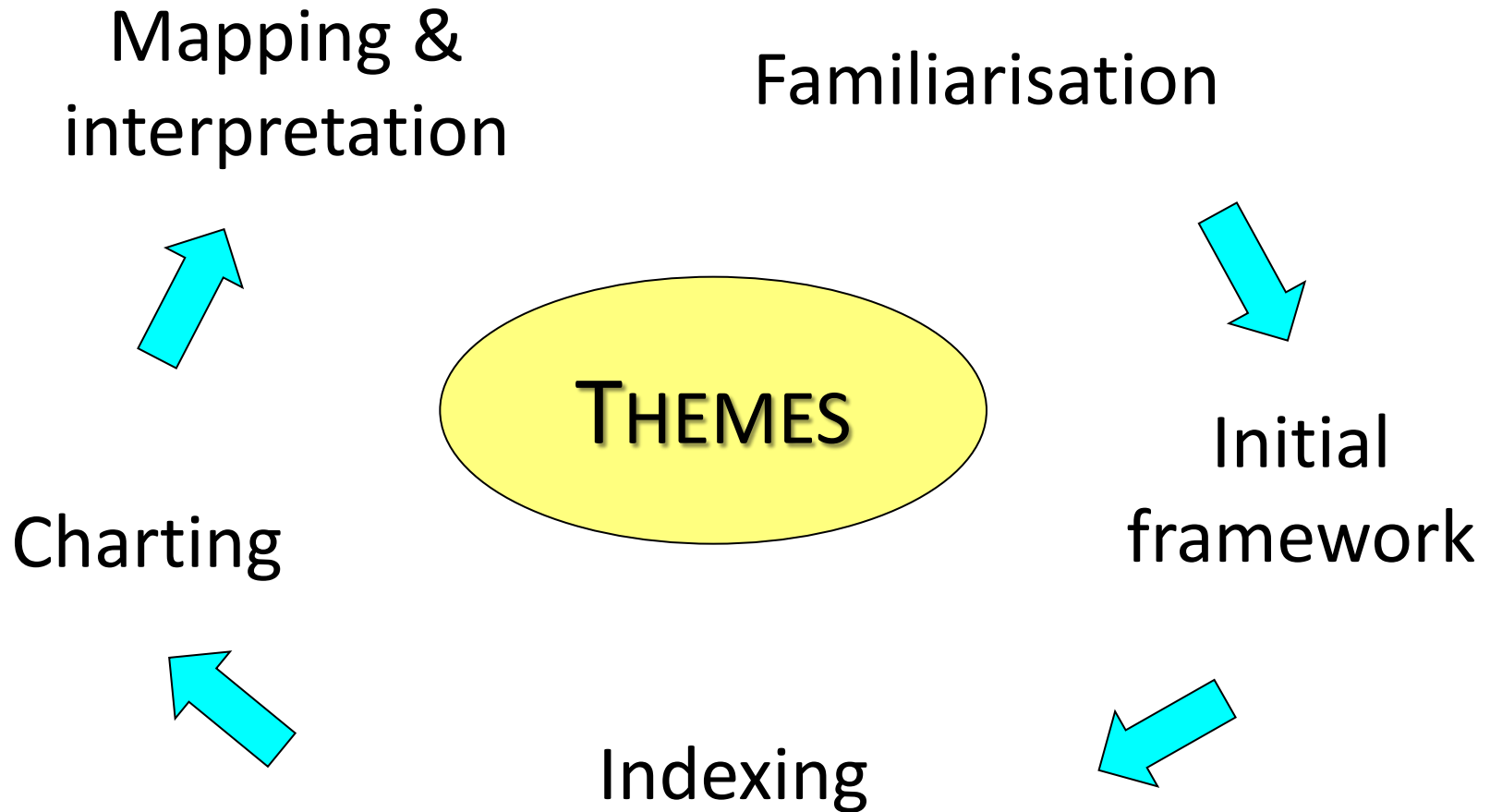
- Reviewed in full by the primary author & a research assistant
- A second reviewer independently screened 10%

- **Full text reports**

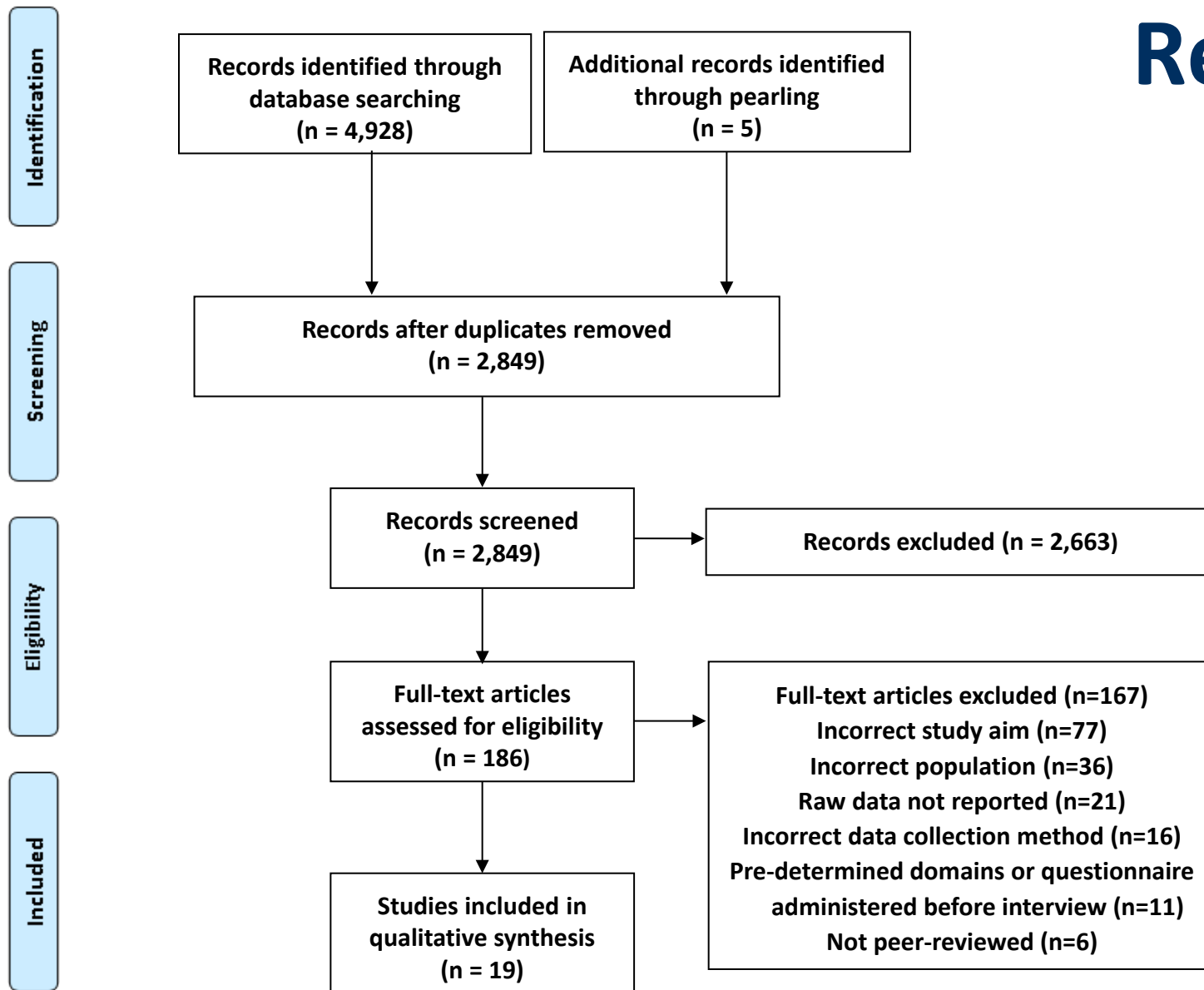
- Retrieved for all citations appearing to meet the inclusion criteria or where there was uncertainty
- Reviewed by the primary author
- Pearling



# Data analysis



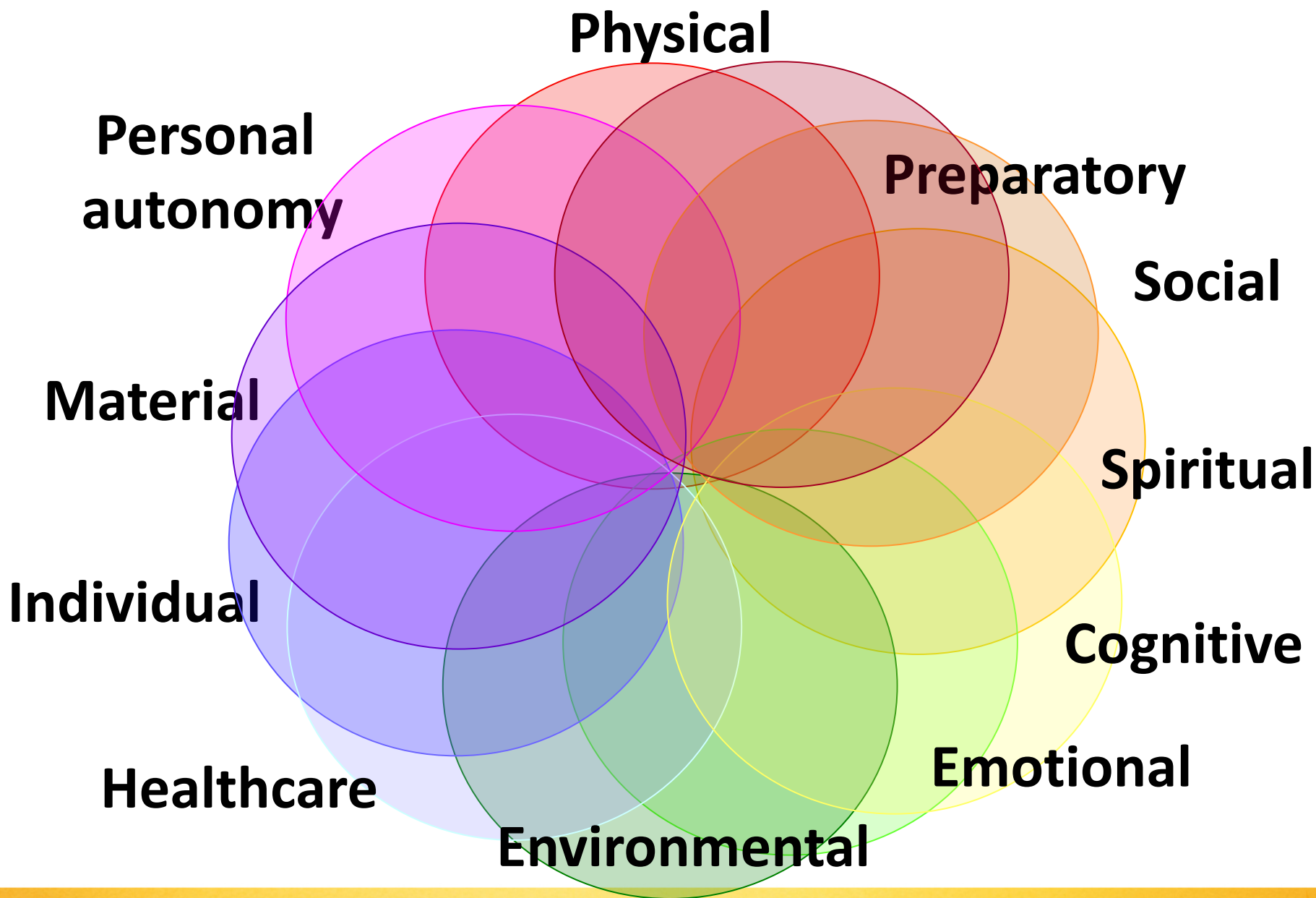
# Results



# Included studies

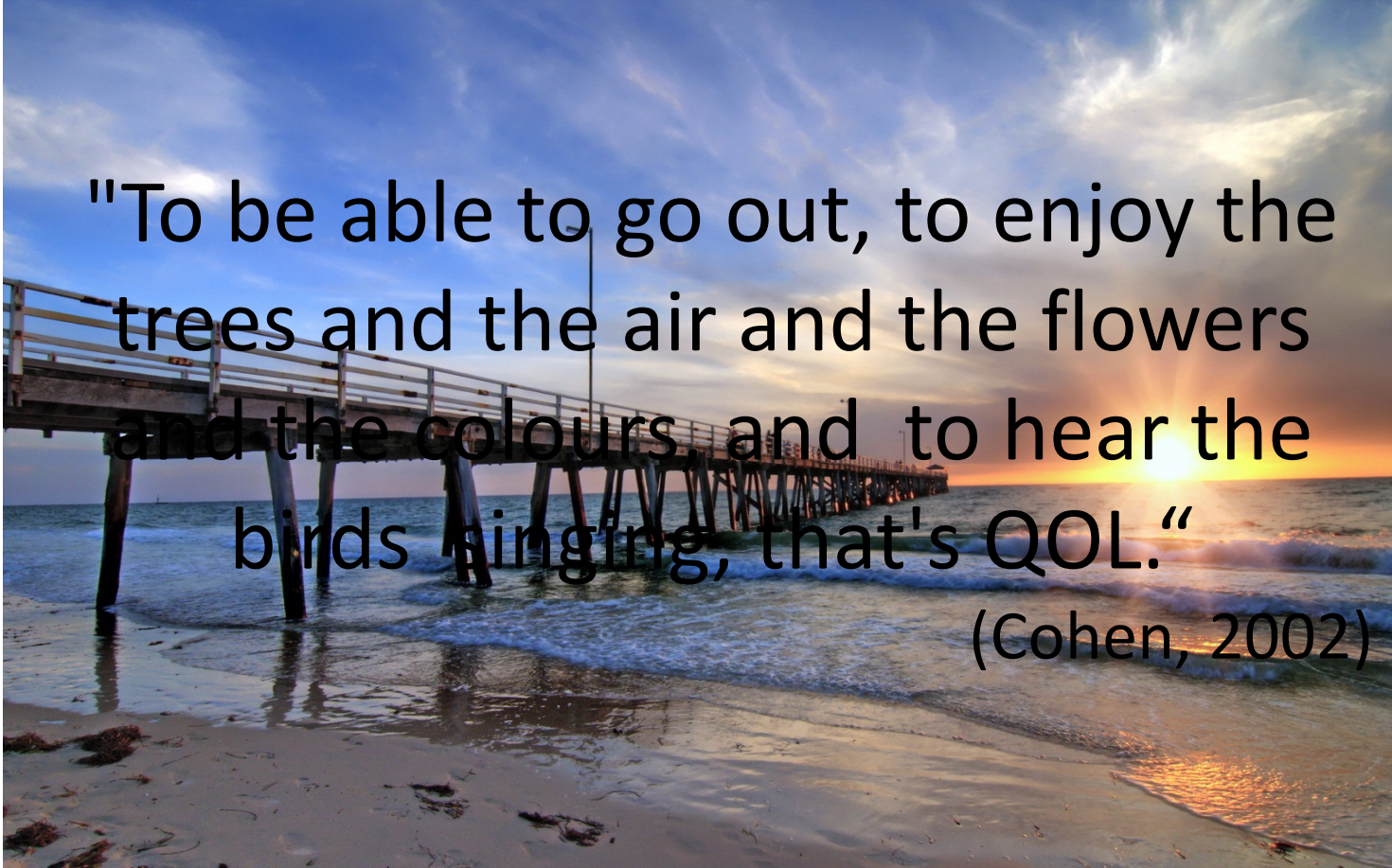
Country		Setting		Diagnoses		Focus		Type of analysis	
Australia	1	Community	10	Cancer	12	QOL	12	Thematic	5
England	3	Hospital	2	HF	2	GD	7	Content	4
USA	5	Hospice	3	AIDS	2			Grounded Theory	3
Canada	3	Mixed	4	Mixed	3			Coding	3
NZ	1							Hermeneutic	1
S Africa	2							NS	3
Sweden	1								
Korea	1								

GD = good death; HF = heart failure; NZ = New Zealand; NS = not stated;  
QOL = quality of life





# Environmental



"To be able to go out, to enjoy the trees and the air and the flowers and the colours, and to hear the birds singing, that's QOL."

(Cohen, 2002)

# Personal Autonomy

"My responsibilities toward my life, my body, my decisions - I'm in control of that  
"I guard my independence. I want to do  
...I am the one that will say what I want  
what I can for myself. I am no different  
...He has given me a tool that will give  
me from other people who are in life  
me QOL till the end, and I think this is a  
threatening situations."  
great gift that I have received."

(Sherman, 2001)  
(Gourdji, 2009)



# Preparatory

“We have spoken about so many things. . . we have our own home, have a very large garden and are both avid gardeners; now she [wife] has to do it all by herself. And it may sound a bit strange but we have had time to discuss how to do the chores...It is maybe a bit weird to say, to organize these materialistic things now, but you worry about it. I don't think I'm the only one who wants to leave everything behind as good as possible.”

(Goldsteen, 2006)

# Spiritual

Security Meaning  
Comfort Existential Faith Role  
“I’ve no fear of dying. I used to have. I used to  
think, how will they know if I’m dead, you  
“My life has a great deal of meaning. I know  
know, all sorts used to go through my mind  
that I have served my fellow man, and that’s  
but not now. I think I’ve eternal life so I’ve  
one of the keys to having a happy life.  
that to look forward to, so that’s all right as  
(Greisinger, 1997)  
well. No, I’ve no fear of dying.”

Support Connectedness  
Strength  
Feeling Expectation (Gott, 2008)

WordItOut



# Thematic patterns?

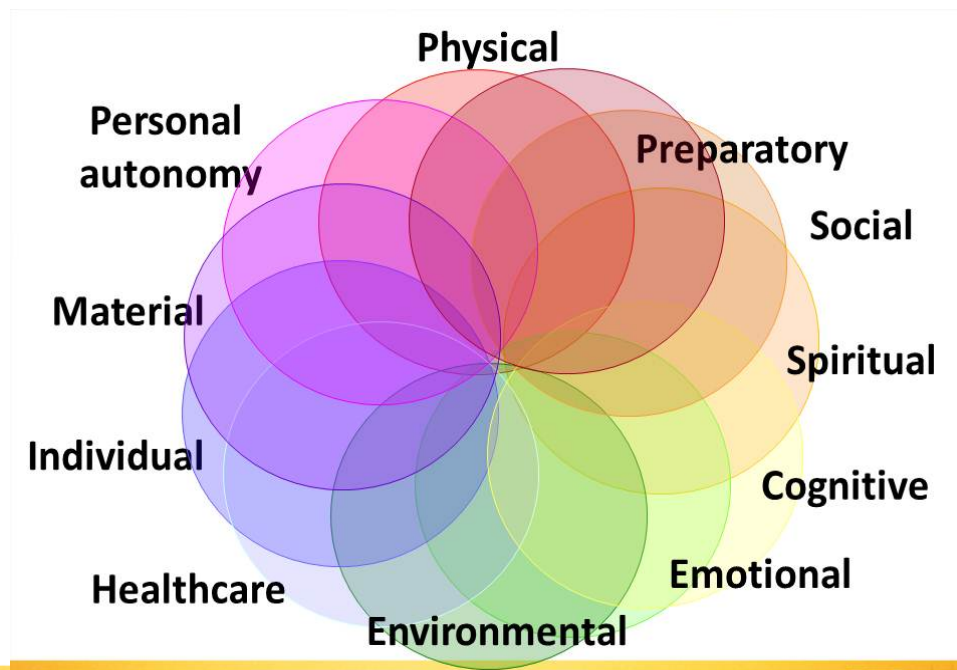
- Individual studies (N=19)
  - All reported emotional and spiritual aspects
  - Most reported physical (n=18), social (n=18) and individual aspects (n=14) and aspects of personal autonomy (n=14)
- Study characteristics
  - Only American (n=5) & Canadian studies (n=3) included cognitive aspects
  - Only Canadian & New Zealand studies, and those including participants with cancer mentioned the environment
  - Preparatory aspects mentioned in studies conducted in all settings, except hospice only

# Implications

Questionnaire	Domains/ dimensions
EQ-5D	Anxiety; pain; mobility; self-care; usual activities
SF-6D	Mental health; pain; physical function; role limitation; social function; vitality
HUI3	Ambulation; cognition; dexterity; emotion; hearing; pain; speech; vision
AQoL	Coping; independent living; life satisfaction; mental health; pain; relationship; self worth; senses

# Conclusion

Popular, preference-based instruments such as the EQ-5D and SF-6D are inappropriate as stand alone measures of benefit in palliative care economic evaluations



**Thematic findings**



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# Quality

## Carroll et al reporting quality criteria

1. The question & study design

Choice of design given & explained

2. The section of participants

Explicitly described, eg purposive

3. Methods of data collection

Details provided, eg topic guide for interview

4. Methods of analysis

Details given, eg transcription & form of analysis